

## ImproveCareNow Data Sharing Expectations

A primary goal of ImproveCareNow is to create a community of patients, families, clinicians, and researchers working together to maximize the likelihood of finding treatments and cures for children with Inflammatory Bowel Disease. Fundamental to reaching this goal is establishing an open approach to sharing data, a strategy advocated, and often required, by many funding agencies. A more open approach to data sharing facilitates the flow of information and knowledge to all community members by reducing the cost, time, and effort required to learn from the data patients have invested. This in turn accelerates the application of discoveries made to improving patient care and outcomes. Achieving ImproveCareNow's goal requires that we outline the norms and expectations that will guide the process of data sharing within and outside the ImproveCareNow Network and allow us to evolve into an open-source database in the future.

### Who is eligible?

- Qualified researchers, who are working at, or affiliated with, accredited universities or hospitals with an Institutional Review Board (IRB). At the present time, researchers not affiliated with ImproveCareNow will be required to work in collaboration with at least one ImproveCareNow affiliated researcher.

### Researchers are expected to:

- Use the data for research that they conduct.
- Allow others under their supervision to use the data for research.
- Submit their research for publication within 12 months of receiving the data in order to facilitate an orderly flow of research ideas.

### Under the following conditions:

#### Data

- Researchers must take appropriate steps to maintain data security (i.e. data cannot be downloaded onto laptop, desktop or flash drive, etc. but must be maintained on password protected server).
- Researchers may not transfer or distribute the data.
- Researchers may not attempt to re-identify any individual patient in the data, or use the data in a manner that creates harm to any individuals (such as exposing them to insurance or employment discrimination).
- Researchers will receive a full dataset that includes all variables. However, they may use only the data required for the projects proposed and approved by the ImproveCareNow Research Division. No additional projects may be undertaken without subsequent research committee approval. If the terms of this are not met, the ImproveCareNow Research Division Director will contact the relevant Institution's IRB chair to inform him/her that no additional IRB protocols may be approved using the ImproveCareNow data.
- Researchers are expected to re-contribute knowledge to the Network by re-depositing derived data, cleaned data, or knowledge gleaned from the data as appropriate.

#### Publications

- Authorship and acknowledgements must comply with the ImproveCareNow authorship policy, including:
  - ImproveCareNow must be appropriately acknowledged within the manuscript as the data source as well as included in the title.
  - A complete list of ImproveCareNow contributing physicians and institutions must be included in the Acknowledgement section in all publications, either via a URL that links to a page on the ImproveCareNow website or as a complete listing within the publication.
- Researchers must try to make available under Open Access terms<sup>1,2</sup> any publications emerging from this research. If allowed by the journal, pre or post-print publications (pdf) will be stored in an ImproveCareNow repository.
- Researchers must provide access to software and documentation for any computational research so that it is reproducible.

### I agree to all of the conditions and expectations outlined above

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Name (Print and Signature)

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Project Title

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Institution/Affiliation

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Date

Peter Suber. Open Access Overview: Focusing on open access to peer-reviewed research articles and their preprints. June 21, 2004 (revised 11/6/2010)  
<http://www.earlham.edu/~peters/fos/overview.htm>  
[http://en.wikipedia.org/wiki/Open\\_access\\_\(publishing\)](http://en.wikipedia.org/wiki/Open_access_(publishing))